

# Quality of Life and Depression Following Deep Brain Stimulation of the Subthalamic Nucleus (DBS-STN)

## INTRODUCTION

The impact of DBS-STN on quality of life (QoL) and depression in people with Parkinson's disease is of great importance and is only in the nascent stages of being understood. Research has shown that depression is especially prevalent in PD patients, with some estimates as high as 50%. However, only a scant number of studies have examined depression following DBS-STN. Of those conducted, most studies indicate that patients experience either no change or some improvement in depression following surgery. Quality of life often improves as well, although not in all areas. At this point in time, there remains a paucity of research that explores the interwoven aspects of depression and quality of life in PD patients who have undergone the DBS-STN.

## OBJECTIVES

- To examine quality of life and depression in a sample of PD patients who have undergone DBS-STN.
- To examine how certain patient and clinical variables (e.g., age, gender, disease duration, time since DBS, and other features) relate to aspects of QoL and depressive symptoms.
- Ultimately, our research goal is to establish a large, representative cohort of DBS-STN patients who can be surveyed at regular intervals (e.g., every 6 months) so that change across time, in multiple areas (neurologic status, quality of life and health, etc), can be better understood. Although these research methods are more *descriptive* and *exploratory* than truly *experimental*, they nonetheless can contribute to the scientific understanding of how PD patients experience, cope with, and benefit from DBS-STN. Such data are especially important given that few long-term outcome studies of DBS-STN exist.

## METHODS

A mail-survey/questionnaire methodology was used. The participants were recruited from a variety of sources. Some had completed previous surveys conducted by the Parkinson Alliance (Tuchman et al., 2003; Tuchman, et al., 2004), others learned about the study on our website ([WWW.DBS-STN.ORG](http://WWW.DBS-STN.ORG)), others responded to study announcements in medical clinics around the country, and still others found out about the study through their participation in local PD support groups. Each participant completed a PD/DBS-specific measure of quality of life (Kuehler et al., 2003), the Beck Depression Inventory-II (BDI-II), and a supplemental questionnaire assessing demographics and other clinical characteristics of the sample. Altogether, 108 patients with Parkinson's disease and with bilateral DBS-STN were included in this study.

## RESULTS

The table below summarizes the demographic and clinical information about the sample. We have collected data from a large, representative group of PD patients spanning a broad range of age and clinical features. With an average age of disease onset at 47 years, our sample is split nearly equivalently among those considered early vs. late-onset of PD. Most of the patients (79%) were not working and many (42%) do not drive an automobile.

### *Summary of the demographic and clinical features of the sample*

Table 1.

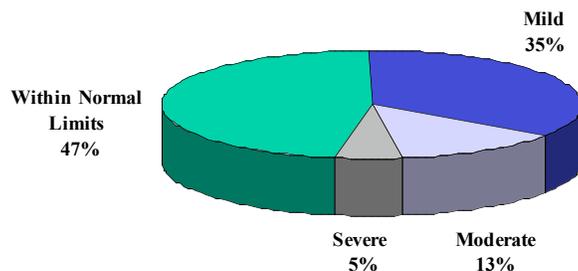
Variable	Mean or Percentage	Range	Standard Deviation
Age	62 years	32-82 years	9.6 years
Gender	62% Male		
Marital Status	79% Married		
Age of PD Onset	47 years	20-67 years	10 years
Duration of PD	15 years	4-27 years	4.7 years
Time since DBS-STN	37 months	5-103 months	17.7 months
Percent Working	79% Not Working		
Percent Driving	42% Not Driving		

### *Summary of BDI-II and Quality of Life Data*

In terms of depressive symptoms, BDI-II scores indicated that 53% (n=58) of the participants scored above the cut-off (score of 10) for at least mild depression (See Graph 1). Table 2 summarizes the clinical variables from the BDI-II and the QoL questionnaire.

Graph 1

#### Severity of Depression: Beck Depression Inventory-II



n = 108

**Table 2. Descriptive Statistics for the BDI-II and the QoL Questionnaire.**

<b>Variable</b>	<b>Mean</b>	<b>Standard Deviation</b>	<b>Range</b>
<b>BDI-II</b>	12.56	8.82	0 to 54
<b>QoL – Overall Life Satisfaction</b>	7.26	5.07	-7 to 20
<b>QoL – Health Satisfaction</b>	5.08	5.98	-9.75 to 18
<b>QoL – Movement Disorders Satisfaction</b>	3.80	5.17	-9.42 to 17.17
<b>QoL – DBS Overall Satisfaction</b>	10.47	5.04	-.6 to 20

QoL varied considerably across participants, with scores ranging from very high QoL, health and PD-related quality of life satisfaction, to very low levels of overall QoL. Higher scores on the QoL measure indicate better quality of life. Higher scores on the BDI-II indicate higher levels of depression. BDI-II scores were significantly correlated with Overall QoL ( $r = -.51, p < .001$ ), health related QoL ( $r = -.56, p < .001$ ) and movement disorder related QoL ( $r = -.46, p < .001$ ). These results indicate that all components of QoL, except satisfaction with DBS-STN, are strongly related to depressive symptoms. Overall satisfaction with DBS-STN correlated significantly with movement disorder related QoL ( $r = .20, p < .05$ ), but not BDI-II scores or the other measures of QoL.

### ***Relationship Between QoL, Depression, and Other Patient Variables***

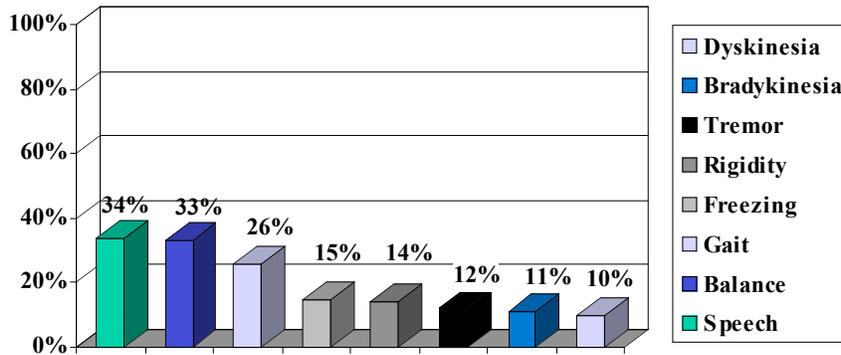
Importantly, age, gender, disease duration, or time since DBS-STN did not correlate with BDI-II scores or any of the QoL measures. Slightly less than half ( $n=53$ ) of the entire sample reported that they have felt sad or blue for a period of two weeks or longer, and 39% ( $n=43$ ) of the entire sample reported being diagnosed with depression in the past. Of the 43 participants who reported a history of diagnosed depression, thirty-three of them reported the onset of depression after the diagnosis of PD. Only 12 participants reported becoming depressed after DBS-STN.

We next compared young-onset ( $<50$  years of age) and later-onset ( $\geq 50$  years of age) PD patients to examine potential differences between these groups. BDI-II scores and all QoL scores were not statistically significantly different between the two groups, suggesting that age of onset does not systematically affect depression and quality of life following DBS-STN.

We asked each participant to list the two most troubling PD symptoms. The data revealed that speech problems were very frequently listed as one of the most troubling symptoms, in addition to cardinal motor symptoms of PD and other motor symptoms. Out of 108 participants, some of the most problematic symptoms in order of most to least reported are speech (34%), balance (33%), gait (26%), freezing (15%), rigidity (14%), tremor (12%), bradykinesia (11%), and dyskinesia (10%) (See Graph 2). Many other symptoms were reported at lower prevalence levels, including fatigue, depression, cognition changes, handwriting, among others.

## Graph 2

### Most Common Troubling Symptoms Reported



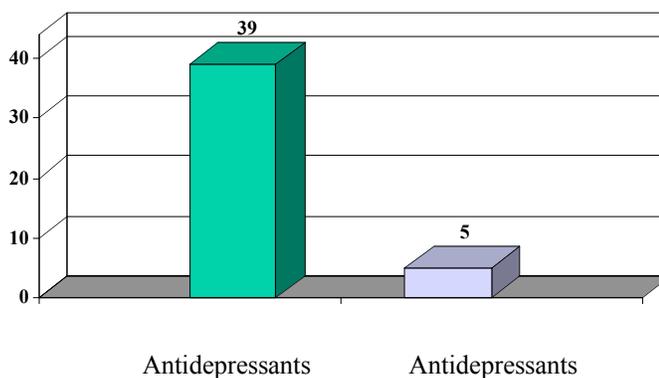
n = 108

To examine the relationships between the most common troubling symptoms and other clinical data, we coded participant data such that if a symptom was endorsed they were coded as “1” and “0” if they did not endorse the symptom. Using these groupings as the independent variable, we examined group differences for those participants reporting speech, balance, gait, freezing, and rigidity as symptoms. There were no particular demographic or clinical features that characterized those who listed speech as a troubling symptom. A trend emerged, however, wherein older patients reported balance and speech problems more often. Age of PD onset did not systematically relate to any of the most troubling symptom groupings.

We also asked about antidepressant medication usage and these findings are interesting and important. As shown in Graph 3, it is clearly evident that the majority of patients receiving antidepressant medication(s) were satisfied with the effects of the medication. Of 44 patients who were taking antidepressant medication, only 5 of them reported that the medication was not working well for them. Although limited to a simple question, these data certainly suggest that most PD patients perceive benefits from such medication.

## Graph 3

### Efficacy of Antidepressant Medications



n = 44

working well

not working well

### ***Satisfaction with DBS-STN***

Most participants reported relatively high levels of satisfaction with DBS-STN. The questionnaire we used contained 5 questions about DBS-STN treatment, including items about satisfaction with doctor care, the reliability of the stimulator, the absence of side effects of the neurostimulation, the inconspicuousness of the stimulator, and the handling/manipulation of the stimulator. The summary rating (i.e., overall satisfaction) on this scale does not systematically relate to age, but there was a trend toward lower overall scores for women (t value = -1.8, p=.062). Inspection of the individual items revealed that women reported significantly less satisfaction with respect to side effects compared to men.

Amount of time since DBS surgery also emerged as a significant predictor of overall satisfaction with side effects, with those participants who have had DBS longer reporting lower levels of satisfaction with respect to side effects. These data suggest that special attention needs to be spent following DBS-STN patients closely across time, as certain aspects of QoL, as it directly relates to DBS-STN, may worsen over time. In many respects, the five questions used in this scale are limited and lead to considerable discussion among our research team about what additional features of DBS-STN surgery are important to assess and monitor over time, and we are especially interested in neurostimulator adjustment issues. We are currently developing a questionnaire to more fully survey these topics.

### **DISCUSSION**

- It must be remembered that this research is descriptive and exploratory, not experimental. Therefore, our findings must be considered in the context of other research conducted in this area and within the limits of the methodology used. With these issues in mind, we offer the following conclusions and points for further research.
- PD patients with DBS-STN showed variable levels of QoL and depressive symptoms.
- Consistent with previous research on non-dbs PD patients, depressive symptoms are prevalent and depressive symptoms most often developed after the onset of PD (Brooks & Doder, 2001).
- A small portion of our sample (12 patients or 11%) reported the onset of depression after DBS-STN. While consistent with the observation that DBS-STN likely does not consistently lead to the adverse outcome of depression, depressive symptoms are to be expected in a sizeable minority of patients. Three of these patients were not currently taking antidepressant medications.
- As expected, depression was highly correlated with quality of life.
- Importantly, regardless of whether or not the participants were depressed or reported low levels of quality of life, they were typically highly satisfied with the experience of DBS-STN.
- Age of PD onset does not appear to systematically affect depression and quality of life following DBS-STN.

- Overall satisfaction with DBS-STN correlated significantly with movement disorder related QoL, but not other domains of QoL (e.g., Overall QoL and health related QoL). This reflects that satisfaction with DBS-STN does not significantly relate to overall QoL or health related QoL, but in contrast, movement related QoL is significantly related to one's satisfaction with DBS-STN. Thus, DBS-STN clearly impacts individuals' movement related quality of life (e.g., ambulation), but other variables also need to be considered when examining quality of life in PD patients who have undergone DBS-STN. These are simply self-report questionnaires and may not reflect neurologic status, such as scores on the UPDRS.
- Those participants who have had DBS longer reported less satisfaction with side effects than those who had DBS for a shorter period of time. These data suggest that special attention needs to be spent following DBS-STN patients closely across time, as certain aspects of QoL, as it directly relates to DBS-STN, may worsen over time.
- Speech, a non-motor symptom, is one of the most frequently reported troubling symptoms among our sample. These findings clearly implicate the need for further exploration and insight into the impact of DBS-STN on speech and its ensuing effects on quality of life. Of note, a trend emerged wherein older patients reported balance and speech problems more often. With regard to the former, the lack of DBS-STN benefit on balance, coupled with commonplace balance problems that tend to occur during the aging process, could explain this finding. With regard to the latter, speech is unequivocally an area of disturbance for DBS-STN patients. However, the etiology remains uncertain – either the exacerbation of speech functioning due to DBS-STN and/or the natural progression of the disease.
- The majority of the participants are satisfied with the effects of their antidepressant medication.
- In spite of the limitations of a questionnaire survey, this kind of exploratory research is necessary to gain a better understanding of the experience of individuals with Parkinson's disease who undergo DBS-STN.

### **FUTURE DIRECTIONS**

- Data on a demographically-matched group of PD patients who have not undergone DBS-STN are currently being collected for comparative purposes.
- The Parkinson Alliance emphasizes the importance of investigating the participants' experience with DBS-STN across time, which will provide for some interesting and substantial longitudinal data.
- Future research is called for to examine in greater degree the etiology of speech disruption as well as the impact of speech disturbance on one's emotional status as well as on one's overall quality of life, particularly as it pertains to the effects of the treatment of speech deficits.
- Understanding the efficacy of specific antidepressants in DBS-STN patients would be a great contribution to the treatment of depression in PD patients, particularly as it pertains to subjective experience of improved QoL.
- Our team has learned valuable information about quality of life research and, after reviewing the available questionnaires used to assess QoL in PD, believe that better instruments can be

developed that will be comprehensive, standardized, and clinically useful. We are currently in the process of developing such a questionnaire.

- Programming and periodic adjustments following DBS-STN are critical in the efficacy of the operation of the stimulator. The Parkinson Alliance is actively involved in sharing the creation and funding of a DBS educational program reform with “WE MOVE.” It is imperative that an avenue be developed to communicate the experiences of the patients in this regard and thus guide less trained individuals to increase the success rate of programming each patient. This relationship between the programmer and the patient will last until we find the cause and cure of this disease. Therefore, we need programmers to understand how to do adjustments to meet specific symptoms of each patient, and better understand the synergy between medication and stimulation.

### **ACKNOWLEDGEMENTS**

As we complete our third DBS-STN patient survey, I am fortunate to still have the support from two People with Parkinson’s (PWP), John Wherry and Richard Kramer, who also had DBS. Their input and data analysis is very important to our work. We also have two psychologists who analyze the data and add their professional skills to our work, including Dr. Jeffrey C. Wertheimer, staff neuropsychologist for the Department of Rehabilitation Psychology and Neuropsychology at the Rehabilitation Institute of Michigan/Wayne State University, School of Medicine. Additionally, I want to acknowledge the dedication and tenacity of Carol Walton, Executive Director for The Parkinson Alliance, as she phoned, wrote, and visited a multitude of DBS facilities across the country to recruit participants for this research project. Furthermore, I would like to thank the rest of the Parkinson Alliance staff for their contributions.

I am very grateful to the people who took time to fill out the survey and to the many care-partners who daily hold the lives of the PD patients together.

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